

Review

Patients using the Internet to obtain health information: How this affects the patient–health professional relationship

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Abstract

Objective: Health information is one of the most frequently sought topics on the Internet. A review of the literature was carried out to determine the use of the Internet for health information by the patient and how this could affect the patient–health professional relationship.

Methods: This study is a literature review, summarizing multiple empirical studies on a single subject and is not intended to be a meta-analysis.

Results: The review showed that the majority of health related Internet searches by patients are for specific medical conditions. They are carried out by the patient: (1) before the clinical encounter to seek information to manage their own healthcare independently and/or to decide whether they need professional help; (2) after the clinical encounter for reassurance or because of dissatisfaction with the amount of detailed information provided by the health professional during the encounter.

Conclusion: There has been a shift in the role of the patient from passive recipient to active consumer of health information. Health professionals are responding to the more ‘Internet informed’ patient in one or more of three ways: (1) the health professional feels threatened by the information the patient brings and responds defensively by asserting their ‘expert opinion’ (health professional-centred relationship). (2) The health professional and patient collaborate in obtaining and analysing the information (patient-centred relationship). (3) The health professional will guide patients to reliable health information websites (Internet prescription).

Practice implications: It is important that health professionals acknowledge patients’ search for knowledge, that they discuss the information offered by patients and guide them to reliable and accurate health websites. It is recommended that courses, such as ‘patient informatics’ are integrated in health professionals’ education.

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Keywords: Internet; Health information; Patient–health professional relationship; Patient–health professional communication

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1. Introduction

Health information is one of the most frequently sought topics on the Internet. Reuters [1] reported that on average 53% of Americans search the Internet for health information and, according to the Pew Internet and American Life Project [2], of the 63% of Americans who access the Internet (128 million people), 66% of these look for health and medical information. In the last decade, the percentage of adults who have accessed the Internet to look for health information has rapidly increased, especially in the United States of America. In 2002, 80% (110 million Americans) of all adults online in the United States were estimated to have looked for health information. This was an increase of 13 million users from 2001 and 50 million from 1998 [3]. Fox and Rainie [4] estimated that, at that time, Internet users could search as many as 10,000 medically related web sites.

With regards to Europe, a recent European Union (EU) Eurobarometer survey on online health information [5] found that, for Europeans, health professionals are still by far the main source of health information (45.3% of EU health population) followed by the traditional media, such as television (19.8%) and newspapers (7.4%). Nevertheless, on average, nearly a quarter of Europeans (23%) use the Internet to obtain health information (this varies between countries, for example, 40% in Denmark and the Netherlands and 15% or less in Greece, Spain and Portugal) and 41.5% of the people within the EU think that the Internet is a good way of obtaining health information [5].

2. Methods

This article is a review article, summarizing multiple empirical studies on a single subject, and is not intended to be a meta-analysis. To review the health application use of the Internet by patients, and how this could affect the patient–health professional relationship and communication, an Internet literature search was conducted on the following health electronic databases: PubMed, British Nursing Index, CINAHL, Ovid and AHMED using the terms ‘Internet’, ‘health information’, ‘patient–health professional relationship’, ‘patient–health professional communication’, limited to the English language and the years 1985–2005. This time frame was selected to reflect the adoption of the use of the Internet to obtain health information. The reference lists of the articles, which ranged from general medical to more specific health

informatics and oncology articles, were scrutinised and relevant articles were obtained.

3. Results

3.1. The use of the Internet by patients and health professionals

Patients do not see the Internet as a replacement for the health professional. A study of 1322 British Internet users indicated that people go online after seeing the health professional for confirmation of the information given and to gather additional information [6]. However, female patients with breast cancer also turn to the Internet for health information if they become dissatisfied with the information provided to them by the health professionals and these information seekers tend to be of higher socio-economic status, younger age and white ethnicity [7]. Internet users searching for health information will even go to sites aimed at health professionals. Of the 220 million searches that are on average performed annually on the National Library of Medicine’s website, approximately 33% are thought to be made by the general public [8]. A survey done by the Health on the Net Foundation [9] ($n = 2621$) found that three out of four non-medical professional individuals (patients or others) reported seeking medical sites or sections dedicated to medical professionals. The main reason given was a preference for access to more complex information (80%) or because they felt that the information usually accessed was too basic (45%). This access to more complex information may raise concerns that patients could misunderstand or become lost in the complexity and amount of medical information. However, 86% of the patients in this survey said they performed alternative searches to clarify information and 32% said they would ask their doctor if they did not understand the information read online.

A study of American Internet users indicated that the majority of those surveyed (91%), both for themselves and for others, searched for medical information about a specific condition rather than for information about healthy lifestyles or healthcare services [4]. This was confirmed in a British study by Nicholas et al. [6]. In their study of 1322 Internet users, 97% accessed the Internet for information about a specific condition, 57% were searching regarding a visit to the doctor and 52% had looked for information about nutrition, exercise or weight control. With regards to online services used, 14% of the respondents participated in an online support group, 10%

used e-mail or gone to a website to communicate with a doctor's office and 8% described a medical condition online to get advice from an online doctor.

3.2. Health application areas of the Internet

There are three main health application areas of the Internet. They are:

- (1) communication, such as e-mail;
- (2) community, i.e. bulletin boards, mailing lists, chat rooms, electronic support groups;
- (3) content, i.e. provision of health information on the Internet.

3.2.1. Communication

The number one reason that Internet users give for using the Internet is e-mail [13]. Daily, world wide, 31 billion e-mail messages are exchanged. However, it is not clear what proportion of this is health related [14]. The advantage of e-mail, with respect to health, is that it can help patients to develop a virtual support network of family, friends and support groups. It also has the potential of enabling them to communicate with health professionals. Electronic communication may help patients to ask questions, facilitate understanding and reduce unnecessary appointments [15]. Surveys have shown that although patients desperately want to use e-mail for communication with health professionals, only 6–9% of patients in the USA have done so [16,17]. The reasons health professionals give for why they are so slow in adopting e-mail with patients include fear of increased demand on their time, confidentiality issues, liability concerns and lack of reimbursement for this service [18].

3.2.2. Community

Electronic support groups are often mailing lists (non-synchronous) exchanging information and support. The advantages over face-to-face groups are the removal of geographical and transport barriers, anonymity and the ability of patients with rare diseases to find peers online. They also reduce feelings of loneliness and depression. The disadvantages can be the quantity of mail, lack of physical contact and the exchange of 'non-evidence based' information [19].

3.2.3. Content

Eysenbach [19] estimated that, on a global level, of the 278 million Internet searches that are being conducted each day, approximately 12.5 million searches are health related. A study of cancer patients showed that most patients who search for specific information about a medical condition do this just after their diagnosis and before starting treatment [20]. Surveys of cancer patients indicate that the two main reasons patients turn to the Internet for information is that

they are dissatisfied with the information provided to them by health professionals [21,22] and to reassure themselves that they have every bit of information available [23]. As a result the expectations that Internet informed patients have of their health professionals change over time as they become aware of the amount of information that is out there that they should receive [19].

The advantage of the Internet is that it is widely available (home, work, libraries), convenient (24 h a day at home) and anonymous [24]. Acquiring increased information from the Internet can improve patients' understanding of their medical condition and self-care, thereby reducing unnecessary visits to the doctor and the burden on the National Health Service (NHS) [25]. There is also a strong relationship between Internet use and patients' self-efficacy and health behaviour. An American survey of cancer patients showed that 92% of patients believe that Internet information empowers them to make health decisions and helps them to talk to their physicians [19], resulting, as the Department of Health [26] hopes, in a more patient-centred interaction between health professional and patient. However, patients in this survey also felt that Internet information can be overwhelming (31%), conflicting (76%) and confusing (27%) [19].

A Canadian study of oncologists found that health professionals see the availability of health information on the Internet as a positive development [21]. However, some health professionals can feel threatened, and their medical authority challenged, by patients coming in with Internet information. They are worried about the accuracy of the information, patients' abilities to interpret the information with the possibility of leading to inappropriate self-diagnosis, and the possible demand of patients for new (unavailable) treatments [12]. They also argue there is simply not enough time in a consultation to respond to patients' questions as a result of the obtained Internet information [27] or enough time to search the Internet to view what their patients may be viewing [11].

3.3. The effect of the Internet health information on the patient–health professional relationship

Traditionally, health professionals were the main providers of information to patients regarding their diagnosis, prognosis and treatment options. Until recently, many health professionals felt that patients were unable to cope with bad news and should be therefore kept ignorant of many details of their illness [28]. However, with the easy access and availability of information through the Internet many patients are no longer satisfied with this attitude. They want to be fully informed and be part of the treatment decision making. A study of women with breast cancer found this especially to be the case with patients who are of higher socio-economic status, younger age and white ethnicity [7]. According to Anderson [27], there are four main factors that contribute to the shift in the role of the

patient from passive recipient to active consumer of health information. Firstly, advances in medicine have led to unrealistic expectations on the part of patients. Secondly, due to the highly specialized care offered by health professionals they are often perceived by patients as being impersonal and aloof. Third, due to consultation time constraints, patients are often left with a sense of frustration and dissatisfaction with the information provided. Fourth, because health professionals may lag behind the patient in terms of familiarity with the use of information technology, such as the Internet, patients often leave the consultation feeling they themselves are better able to seek information about their health condition and treatment options.

4. Discussion and conclusion

4.1. Discussion

Health professionals can respond to the more ‘Internet informed’ patient in three ways. In the first scenario, the relationship between health professional and patient becomes health professional-centred. Health professionals, especially those with poor information technology (IT) skills, may feel their medical authority being threatened by the information the patient brings and will respond defensively by asserting their ‘expert opinion’. They will use the short consultation to quickly and authoritatively steer the patient towards their choice of action [12].

The second scenario is where the relationship between health professional and patient becomes more patient-centred in line with the Department of Health white papers *The NHS plan. A Plan for Investment, a Plan for Reform and Building the information core implementing the NHS plan* [29,26]. In this scenario, the health professional and patient collaborate. After all, many patients not only have the time, but also the motivation to search for information regarding their health problems, and, as they are often only interested in one condition, their search is usually focused. Health professionals, on the other hand, do not have as much time to search for every clinical condition they might encounter, but they do have the skill and knowledge to analyse the information and assess the relevance to the particular patient [11]. “Rather than being intimidated by information overload, doctors may do well to acknowledge the problem and cooperate with patients in changing the concept of whose responsibility it is to ‘own’ the information” [10]. However, some health professionals may still complain there is not enough time in a consultation to respond to patients’ questions as a result of the obtained Internet information [27].

The third scenario is where the health professional recommends websites to patients. Gerber and Eiser [30] call this scenario the ‘Internet prescription’. In this way, the health professional can guide the patient to reliable and accurate information. However, it then becomes important for the health professional not only to know the specific

information, but also where to find it on the Internet. As it is impossible to keep track of all the information that is on the Internet, health professionals should know about reliable quality repositories of health information and medical links [30], such as the National Library for Health or NHS Direct Online. In addition to guiding the patients to high quality websites, Eysenbach [19] suggests that health professionals could also educate and train patients on how to ‘filter’ information. This is presuming that health professionals themselves are educated in this. It is possible that a combination of scenarios two and three could exist to create a patient-centred, professional-guided scenario.

4.2. Conclusion

The Internet has become a major source of health information. It can improve patients’ understanding of their medical condition and their self-efficacy. Additionally, it can empower them to make health decisions and to talk to their physician, resulting in a more patient-centred interaction between patient and health professional. It has also contributed to a shift in the role of patients from passive recipients to more active consumers of health information. In response to the ‘Internet informed’ patient, the patient–health professional relationship can develop in one or more of three ways: (1) the relationship can become health professional-centred with the health professional exerting his or her expert opinion. (2) The relationship can become patient-centred where patient and health professional collaborate in obtaining and analysing the Internet information and (3) the health professional acknowledges the patient’s ‘search for knowledge’ and guides the patient to reliable and accurate information.

4.3. Practice implications

However, for this shift to happen towards patient-centred interaction, it is important that health professionals acknowledge patients’ search for knowledge, that they discuss the information offered by patients and guide them to reliable and accurate health websites. To adequately prepare health professionals to be able to do this, it is recommended that courses, such as ‘health informatics’ or ‘patient informatics’ (i.e. the use of technology mediated information for patients) are integrated in the health professional’s education. For further research, it would be interesting to determine how the relationship will develop between newly qualified ‘Internet informed’ health professionals and their patients and how these health professionals will respond to the more ‘Internet informed’ patient.

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